Texas Birth Defects Monitor

Texas Department of Health

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From the Director

The Texas Birth Defects
Monitoring Division is alive
and very well. Staff in the two
pilot regions, Houston and
Harlingen, are working intensely to attain their
goals for the first surveillance year (1994).
Surveillance has begun for 1995 deliveries as
well.

The Division received some especially good news last spring: \$1,000,000 was appropriated by the State Legislature for expansion of the Texas Birth Defects Registry beyond the two pilot regions. Since the amount is not sufficient to expand statewide, data are currently being compiled that will assist the Division in deciding which public health regions will be covered by the Registry in late 1996. Expansion of the Registry is beneficial for Texas. Children in the Registry receive Departmental referral services, birth defect cluster investigations can be investigated efficiently, and the database is enlarged to enhance our capacity for research.

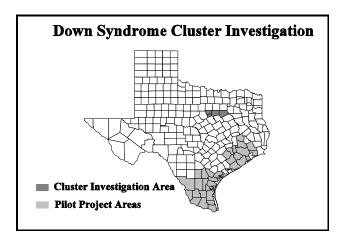
Mark Canfield, Ph.D

Focus on a Cluster Investigation: Down Syndrome

Down syndrome is a relatively common chromosomal abnormality in which an infant receives three copies of chromosome 21 instead of two. The only well–established risk factor is advanced maternal age, although advanced paternal age and exposure to ionizing radiation have also been suggested as risk factors.

An apparent excess of Down syndrome children was initially reported in late 1994 by a staff member from Early Childhood Intervention (ECI),

an agency responsible for providing services to young children with developmental disabilities. The affected children were born in 1992–1994 to mothers residing in Hood County. Four months later, a concerned parent called about excessive numbers of Down syndrome children born during the same time period, two counties away, in Ellis County. To consolidate our efforts, the investigation now encompasses four adjacent counties south–southwest of Dallas/Ft. Worth: Ellis, Johnson, Hood, and Somervell. Since all four are outside of our Registry pilot regions (see map), the search for additional cases utilized further help from ECI, the Bureau of Vital Statistics, and calls from affected families.



To date, there are 18 cases of Down syndrome detected for 1992–1994; four other potential cases await confirmation. This figure represents approximately two times the number of cases expected for the four county area (but higher for Ellis and Hood counties). The number of expected cases was calculated using Down syndrome rates obtained from the California Birth Defects Monitoring Program. (Texas rates will be used once Registry data are available). The Texas Department of Health is currently conducting interviews with the affected families to determine any common risk

factors or exposures. The questionnaire being used is extensive, including questions on maternal medical factors, reproductive history, known occupational or environmental exposures, diet, and the use of herbal remedies, medications, and drugs. Future steps may include interviewing unaffected comparison families.

The Division has consulted on this issue with the members of the Scientific Advisory Committee on Birth Defects in Texas.

For more information, please contact: Peter Langlois, Ph.D. Senior Epidemiologist, (512) 458-7232

Neural Tube Defect Project



In late summer of 1992, Texas Department of Health (TDH) responded to a Centers for Disease Control and Prevention (CDC) request for proposal (RFP) to implement neural tube defect (NTD) surveillance and risk reduction activities in a high prevalence area. The RFP also requested a case—control study for risk factors for NTD occurrence. In October 1992, TDH was awarded funds to carry out these activities in the 14 counties along the Texas—Mexico border: Brewster, Cameron, El Paso, Hidalgo, Hudspeth, Jeff Davis, Kinney, Maverick, Presidio, Starr, Terrell, Val Verde, Webb, and Zapata.

The mission of the Texas Neural Tube Defects Project (TNTDP) is to identify NTD-affected pregnancies in residents of the 14 Texas-Mexico border counties and provide education and folic acid supplementation to these women in order to decrease the risk of recurrence. The TNTDP also conducts research to determine risk factors of NTD.

From 1994 through 1995, 130 NTD cases were identified (64 in 1994 and 66 in 1995). From

January 1, 1993, to June 30, 1995, 80 out of 125 (64%) eligible women have consented and are on folic acid supplementation. The case—control study began in June 1995 and includes a general questionnaire; a food—frequency questionnaire; and laboratory tests of blood, urine, stool, and tissue. To date the study has yielded 60 cases and controls.

Article contributed by TNTDP. For additional information on NTDs or the project, please contact Kate Hendricks, MD, MPH & TM, Russ Larsen, Ph.D., MPH (512) 458-7328 or Scott Simpson, MD at (512) 458-7700

Folic Acid and Multivitamins

Approximately fifty percent of all cases of neural tube defects are preventable with sufficient intake (0.4 mg) of folic acid in the periconceptional period. The Department is moving forward on the folic acid issue in Texas. Two primary issues are now being aggresively pursued:

- 1. an assessment of folic acid knowledge and practices, particularly among women of childbearing age in Texas;
- 2. statewide campaign for folic acid for the primary purpose of preventing neural tube defects.

Fetal Alcohol Syndrome: Voluntary Reporting

Health providers in the two pilot regions of the Texas Birth Defects Registry are reminded to report cases of fetal alcohol syndrome directly to the Division. Although the Texas Birth Defects Registry is based on *active* case ascertainment, this activity is based largely in health facilities, mainly hospitals. It is well established that fetal alcohol syndrome is not well ascertained from birth hospitals. To get a better picture of this preventable condition, we request that physicians and other providers who diagnose and manage this condition report cases directly. This can be done through the use of a voluntary reporting

form available from the Division. Confidentiality is maintained by law.

Referral of Children with Birth Defects

The referral of children with birth defects was an important part of the Birth Defects Act. The Division is finalizing its procedures for the referral of infants and young children identified by the Registry. One important note: with the help of Regional Children with Special Needs Program (CIDC)/social work programs, the Division intends to evaluate this referral program from its inception.

A Move Ahead

The Houston Regional Office is moving in mid-December. The new address/phone:

> 5424 Polk Avenue, Suite J Houston, TX 77023-1497 (713) 767-3310

Selected Recent Reports Available

Health Studies Program, Bureau of Epidemiology, Texas Department of Health. Epidemiology of Neural Tube Defects in Two Texas Border Counties, 1980-1992. (Includes active surveillance and trend data on anencephaly, spina bifida, and neural tube defects in Cameron and Hidalgo Counties.)

Texas Neural Tube Defect Project, Texas Department of Health. Primary Prevention of the Recurrence of Neural Tube Defects. Annual Report. July 1995. (Includes data on neural tube defects for Texas-Mexico border counties, 1993 and 1994.)

CDC. Economic Costs of Birth Defects and Cerebral Palsy - United States, 1992. MMWR 1995;44:694-699.

CDC. Knowledge and Use of Folic Acid by Women of Childbearing Age - United States, 1995. MMWR 1995;44:716-718.

CDC. Disabilities Among Children Aged #17 Years

United States, 1991-1992. MMWR 1995;44:609-613.

CDC. Surveillance for Anencephaly and Spina Bifida and the Impact of Prenatal Diagnosis - United States, 1985-1994. MMWR/CDC Surveillance Summaries 1995;44(SS-4).

Thanks for the Clinical Review

Abstracted cases of birth defects often require clinical review, sometimes at more than one level. This assures consistency and greater accuracy for the Texas Birth Defects Registry.

Thanks to the three clinical reviewers who have assisted the Division in 1995:



Angela Scheuerle, M.D. Judith Martin, M.D. Margaret Drummond-Borg, M.D.

Thanks for the Notebooks



Since our offices opened 17 months ago, five notebook computers have been purchased for the Division by several programs within the Associateship for Disease Control and Prevention. We would like to acknowledge these programs for their assistance:

Diabetes Council, Bureau of Chronic Disease Prevention and Control

Bureau of HIV/STD Prevention and Control

Immunization Initiative

These notebooks are being used by field people in the two pilot regions (Houston and Harlingen) to gather information on birth defect conditions covered by the registry. Cases of birth defects that relate to diabetes, syphilis, and rubella are covered as well. The *Texas Birth Defects Monitor* is published by the Texas Department of Health

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David R. Smith, M.D. Commissioner of Health

Diane Simpson, M.D., Ph.D. State Epidemiologist and Associate Commissioner, Disease Control and Prevention

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Gladys Sánchez, M.S. Associate Editor Fetal Alcohol Syndrome Surveillance/Prevention Project To be added to the mailing list for this or other free publications from the Division, please call (512)458-7232 or use the following e-mail address: swicker@epi.tdh.state.tx.us

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Address Correction Requested